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Developing Cancer-Related Educational Content and Goals Tailored to the Comanche Nation

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Abstract

Cancer-related educational content and goals should be modified to the needs of Native Americans to ensure adherence to healthy lifestyles. The current article describes the development of cancer-related educational modules that include creating behavioral goals specific to the people of the Comanche Nation. A community-based participatory research approach was used to conduct focus groups in the Comanche Nation and obtain feedback related to cancer-related educational modules and behavioral goals. Content analysis, verbatim transcriptions, field notes, and observations were used to analyze data and create five major themes. Comanche people need cancer educational modules and goals tailored to their culture to become engaged and maintain interest, thereby improving the likelihood of increasing cancer-related knowledge. Oncology nurses should respect guidance provided by Comanche community members to adapt cancer-related education materials and processes, as well as goal development, to address cultural concepts. When Comanche community members become knowledgeable and work toward healthy behavioral change, cancer health disparities may decrease.

Keywords

medically underserved; health disparities; cancer program development/evaluation; cultural aspects; patient/public education

Despite implementation of cancer educational strategies that have reached some Native Americans (NAs), no strategies have been tested within the Comanche Nation. About 15,000 Comanche people live in the United States, and 8,000 live in southwestern Oklahoma (Comanche Nation of Oklahoma, 2011). Because of their proximity to one another, they are able to maintain many distinct cultural beliefs and practices. The current article describes the first year of a three-year project in which researchers examined content and process needs for tailoring cancer-related educational modules to the Comanche Nation, as well as the creation of behavioral goals related to each module.

Background and Significance

NAs of the southern plains (e.g., Oklahoma, Texas, Kansas) and northern plains (e.g., Nebraska, Montana, North Dakota, South Dakota, Wyoming) share higher cancer incidence and mortality rates than NA people living in other states for some cancer types (e.g., lung, breast, prostate, cervical) (Espey et al., 2007). Oklahoma is the primary source for cancer data in the southern plains (Havercamp, Espey, Paisano, & Cobb, 2008). However, no tribe-specific cancer data exist for the Comanche Nation, which is located within the Lawton Service Area of the Indian Health Service (IHS), an area that encompasses 10 counties in southwestern Oklahoma. In this area, the incidence rate per 100,000 people for all cancers is higher (554) than the Caucasian population in the state (488) and all races combined (493) (IHS, 2009).

Cancer-Related Education Among Native Americans

Information related to cancer education among NA people is sparse. Eschiti, Burhansstipanov, and Watanabe-Galloway (2012) found four studies relating to cancer education provided to NAs. After receiving education about cervical cancer, Crow women in Montana had increased knowledge of Papanicolaou tests and cervical cancer (Christopher, Gidley, Letiecq, Smith, & McCormick, 2008). Christopher et al. (2008) reported that the women had increased comfort in discussing cancer issues and requested Papanicolaou tests more often. Burhansstipanov et al. (1998) found that 90% of NA women receiving breast cancer education had mammogram rescreening in a sample from Denver, CO. In the Native Women's Wellness Through Awareness project, NA women who received breast cancer education in Denver showed increased recruitment to mammography screening, compared to prior to the start of the program (Burhansstipanov, Dignan, Wound, Tenney, & Vigil, 2000). Burhansstipanov et al. (2010) noted that NAs in Los Angeles, CA, who received an intervention for breast cancer education face-to-face or by telephone reported more rescreening mammograms in all racial groups.

Educational modules have been developed by the Native American Cancer Research Corporation (NACR) but do not address behavioral goals or the unique cultural characteristics of the Comanche Nation. The modules were created for urban NA populations that have been relocated from other areas. In contrast, the Comanche people are largely located in rural areas and are one of the few tribes in Oklahoma who still live on ancestral lands and maintain many cultural practices.

Research Purpose and Questions—No peer-reviewed literature exists on the development and implementation of goals related to cancer behaviors involving NAs, and no information exists on how to develop cancer-related educational workshops or behavioral goals tailored to the needs of the Comanche people. Because of their unique cultural practices, cancer education must be made culturally appropriate.

The objectives of the first year of the project were to modify the NA cancer-related community workshop content to be culturally and geographically appropriate for the Comanche Nation prior to workshops and to create culturally appropriate goals for each cancer-related workshop module. The subsequent two years of the study included delivery and testing of the educational modules and behavioral goals. Researchers asked the following questions.

- How should NA cancer-related community workshop content be modified to be culturally and geographically appropriate to Comanche Nation community members?
- What are the components of culturally appropriate behavioral goals for cancer-related workshop modules created for Comanche Nation community members?

The Health Belief Model is the most commonly used theory in health education and promotion (Janz, Champion, & Strecher, 2002). It has been used with NA populations previously (Becker & Foxall, 2006) and serves as the framework for this study. Educational workshops may serve as a call to action that would increase awareness of the threat of developing cancer, diminish perceived barriers to receiving screening and treatment, and enhance the likelihood of behavioral change. Changes may include scheduling a colonoscopy, improving nutrition, or increasing activity levels.

Cancer-Related Education Modules

Cancer-related educational modules developed by NACR are in Microsoft PowerPoint® format and cover topics from cancer prevention to end-of-life care. Each module consists of learning objectives, definition of terms, and pertinent information. An interactive activity is included in each module to facilitate participant involvement in active learning.

TurningPoint®, an audience response system, is used to increase interactivity. The system consists of a keypad with numbers from 0–9, similar to a palm-sized calculator. Participants can anonymously respond by pressing a number that corresponds to the numeric response they choose, which can be saved as a Microsoft Excel® file. The current study adapted NACR modules to suit the needs of the Comanche community. The topics of the modules presented to the community included cancer basics, energy balance, healthy eating, palliative care, survivorship, and advanced directives and wills.

NACR's modules had not been presented to the Comanche Nation, so it was necessary to modify them by engaging local community members in revisions (Haozous, Eschiti, Lauderdale, Hill, & Amos, 2010). For example, cultural modification may involve deletion of a generic image of a NA person and replacing it with a photograph of a Comanche person dressed in traditional regalia. It also may entail adding words from the Comanche language.

Inclusion of behavioral goals related to the content of each of the 12 modules allowed participants the opportunity to select personal goals of interest. Goals were created by two Comanche native navigators and the principal investigator (PI). Native navigators are trained NAs who assist others through the cancer healthcare system from prevention to end-of-life care. Goals were modified further during focus group sessions.

The Goal Attainment Setting tool was used to measure cancer-related behavioral change because it provides a meaningful way to assess progress toward achieving goals over time (Becker, Stuijbergen, Rogers, & Timmerman, 2000). It has been shown to be a valid and reliable tool (Kiresuk, n.d.). A Likert-type scale was used to indicate the expected goal attainment outcome (0), a somewhat better-than-expected outcome (+1), a much better-than-expected outcome (+2), a somewhat less-than-expected outcome (−1), and a much less-than-expected outcome (−2) (Stuijbergen, Becker, Blozis, Timmerman, & Kullberg, 2003).

Methods

The current study used a multidisciplinary approach between nurses and public health practitioners guided by the principles of community-based participatory research (CBPR). This collaborative approach allows partners to contribute equally and share decision making and ownership (Israel, Eng, Schulz, & Parker, 2005). The approach lends itself to working with medically underserved populations, such as NAs, who historically have been victimized by unethical research practices (Hodge, 2012).

Many tribal nations consider CBPR to be the method of choice when partnering with researchers (Burhansstipanov, Christopher, & Schumacher, 2005). The researchers in the current study used an exploratory, descriptive, qualitative approach with focus groups that reviewed content, comprehension, cultural appropriateness, and ability to engage participants to create cancer-related educational modules and behavioral goals (Sandelowski, 2000).

Sample

The purposive sample consisted of 23 key informants who ranged in age from 21–90 years and were recruited via word of mouth by the PI and two native navigators (see Table 1). Participants were selected for their knowledge and insights of the Comanche culture, health education needs, and age-related considerations. The participants' varied backgrounds, ages, educational levels, and willingness to participate allowed for a breadth of health education insights that were representative of the Comanche Nation. To the authors' knowledge, none of the participants participated in any previous educational cancer workshops given by NACR.

Study procedures were approved by the institutional review board of the University of Oklahoma and the Comanche Nation. Consent forms containing the study purpose and protocols were given to potential participants at least one week prior to the interviews to allow time to receive additional information and clarification from the PI before signing the consent form.

Data Collection Procedures

A meal was provided prior to the start of data collection because sharing food is a cultural expectation. Demographic information was collected via written questionnaire, and the focus group process was described orally by the PI. All participants were assigned a color code name to ensure confidentiality. An interview guide was used to facilitate the discussion (see Figure 1). Main points discussed were written on a large pad on an easel using colored markers so participants could view ideas presented and comment on them. All focus groups were transcribed verbatim, with field notes and observations added to the data for analysis.

Four focus groups, each with six to seven participants, were held during a three-month period in a private conference room at the Comanche Nation tribal complex. Two focus groups were held during the day and two were held in the evening to accommodate different working hours of participants. The length of each focus group was 60–90 minutes for a total of six hours.

Focus group facilitators included the PI and two native navigators. The PI is a nurse who lives in the Comanche community, participates in Comanche cultural activities, and has expertise in research with NA populations. In addition, a Comanche nurse with expertise in conducting qualitative analysis was the project consultant. Consistent with the CBPR approach, members of the Comanche community were provided with opportunities for learning new skills. The native navigators were trained as focus group facilitators and were effective because they grew up in the Comanche community, were known to the people, and used colloquial language.

Each focus group reviewed portions of two modules, so 8 of the 12 modules were reviewed. All aspects of the module format were discussed by the end of the focus groups. Participants provided guidance on phrasing and concepts of goals to be modified. For example, participants suggested the goal, “I will decrease my intake of table salt immediately.” This goal was preferred over reading food labels for sodium content because participants felt it was more realistic and feasible. They were instructed how to use TurningPoint keypads to answer questions as they evaluated the various modules and the technology used in the learning process. Participants were given \$30 gift cards to thank them for their time and insights. Participants were informed that some people would be provided with excerpts of their comments to review for accuracy.

Analysis

Content analysis of the data from focus group responses, field notes, and observations were recorded (Morse, 1994). All data were reviewed by the PI, the qualitative project consultant, and native navigators. Research team members developed consensus on code categories and emerging themes. Once completed, the themes and supportive quotes were shared with select participants to ensure accuracy and validation. Clarifications were noted; however, no theme modifications were required.

Evidence of Rigor

Credibility was achieved through validation from focus group data, audio recordings, field notes, and observations. Credibility was enhanced by participation of the PI who is experienced in culturally sensitive research methods, as well as the Comanche native navigators and the Comanche qualitative analyst who were familiar with the culture. Trustworthiness was confirmed when the findings provided rich descriptions of experiences that were substantiated by participants (Morse, 1993).

Transferability was enhanced by including men and women of varied ages, education, and life experiences. That allowed for a broad understanding of the topic under investigation, making the findings representative of the data from which they originated (Morse, 1993). Focus groups ended after all pertinent areas for discussion were covered and no new information was identified, as deemed by the facilitators.

Findings

Five themes and related subthemes emerged from the focus group data analysis. The five major themes included (a) Screening Is Protection, and Knowledge Is Power, (b) Waiting, Not Acting: Fears Associated With Screening, (c) Living Native Strong: Assessing Personal Risk, (d) Nourishing Body, Mind, and Spirit: Connecting With the Past, and (e) Keeping Learners Interested: Educational Engagement. The five themes supported the need to address Comanche cultural perspectives and highlighted the importance of participants' ancestry and healthy lifestyles to decrease risk of cancer development.

A model for developing content was generated using the five themes (see Figure 2). The model of developing cancer-related educational content and goals incorporates the seal of the Comanche Nation. The left side of the seal is blue with an undulating edge. The right side is yellow and bears the red image of a Comanche warrior on horseback. The red color of the warrior stands for the “red man,” a term that refers to NA people. Yellow symbolizes the brightness of the sun and a state of happiness, and blue stands for loyalty. The blue and red colors are derived from wool trade blankets used by the Comanche more than 100 years ago when riding horseback across the plains. The curved line represents a snake moving in a backward motion, as the Comanche were known historically as the Snakes (Healy, n.d.).

Screening Is Protection, and Knowledge Is Power

Discussions indicated a need for cancer screening through education and empowerment. Participants identified the importance of incorporating Comanche stories that related their beliefs about health and illness in cancer education. Participants believed that graphic images would engage and maintain an audience's attention. Participants identified “strong impressions” as motivators for screening by embedding NA visuals in education program photographs, videos, handouts, stories, and diagrams. Participants said that using a “buddy system” to support and motivate friends and family by being with them during screening would be essential. Participants discussed blending medicines, which would allow a blend of the health and illness beliefs of NA people with those of Western medicine by the inclusion of traditional healers, using a list of NA community contacts by hospitals and clinics that

included names of traditional healers and spiritual leaders, and improving the cultural competency skills of providers.

Waiting, Not Acting: Fears Associated With Screening

Fears associated with cancer screening included unfamiliar terms, variance in screening procedures, and concern that their voices were not being heard in relation to information sharing and discussion with providers. One participant spoke about screening behaviors in NA people.

I think the hardest thing for an Indian is to go in to have [screening] done. They're not going to go in on their own. They're going to wait until they have some kind of symptom before they go in, especially men. I think that's the hardest thing for the Native Americans right now.

Other issues raised by participants included lack of IHS funding for screenings, poor equipment, and that cancer screening was perceived as a low priority for IHS.

Living Native Strong: Assessing Personal Risk

Although participants understood components of a healthy lifestyle, they identified challenges in getting exercise, making healthy food choices, maintaining food portion control, interpreting media food messages, and including government food commodities (supplemental nutritious food) in their diets. Participants felt their community needed information on how to supplement commodities to improve nutrition content. Family health history and genetics were seen as important in understanding risk for developing cancer.

Nourishing the Body, Mind, and Spirit: Connecting With the Past

Participants hoped to appreciate, recapture, and sustain the lifestyles of their ancestors, who were hunters and gatherers, by performing daily exercise and keeping a healthy diet. Their nomadic ancestors gathered roots, berries, and nuts by hand, preserved and used animal hides for clothing and shelter, and moved with seasonal changes. They ate natural food without preservatives that was low in fat and high in protein and fiber, and they prepared foods over open flames rather than by frying.

Focus group participants wanted to share stories of tribal members who were cancer survivors. One participant shared a story of a female Comanche breast cancer survivor from the Path to Breast Health module that illustrates the connection between body, mind, and spirit. The participant said, "Spirituality is harmony. And to have harmony means to have a clean heart, a clean body, and a clean mind. These things will give you strength in all things."

Keeping Learners Interested: Educational Engagement

Participants identified ways to keep learners interested and engaged in cancer education. They noted potential methods of interactive activities, tailoring module topics, individual goal setting, and tools and content used to educate. Participants agreed that the TurningPoint keypads kept them interested in the presentation and helped them retain information.

Content for each module was decreased to maintain interest. One participant mentioned that a picture or diagram would be helpful and said, “Many of our people are very visual. A little diagram would do a world of good.”

Individual, realistic goal setting was seen as possible with the correct information, support, and follow-up from those knowledgeable about cancer. As a result of goal modification, the following goals were added to the Path to Colon Health module: (a) I will increase the amount of fiber in my diet within three months, (b) I will get a fecal occult blood test within six months, and (c) If I am at high risk or have average risk and am age 50 or older and have not had a colonoscopy, I will get a colonoscopy within 12 months.

Perhaps the most telling recommendation made was the group members' belief in the significance of embedding all educational materials, handouts, videotapes, and slides with NA identity. All agreed that the most powerful learning came from listening to personal narrations of Comanche survivor stories and seeing photographs. That was perceived as a message of hope, that surviving cancer is possible. One participant said, “I think people need to see our people that are surviving [cancer].”

Discussion

Participants indicated that Comanche cultural beliefs are so embedded within their lives that they must be incorporated into cancer-related educational programs and behavioral goals, which is significant because Comanche culture and practices are generally healthy and potentially can decrease the risk of developing cancer. Unlike the approach used for cancer-related education of urban NAs in Denver and Los Angeles (Burhansstipanov et al., 1998, 2000, 2010), the approach for the Comanche Nation requires cultural tailoring. Comanche people want to acknowledge and honor their distinct cultural beliefs and practices in the slide presentations as a way to show that traditional ways of knowing are valued and respected.

For example, a slide for the Path to Prostate Health educational program created by NACR contained the NACR logo and refers to NA men from the northern plains with no photographs. After adapting the slide to the Comanche Nation, it contains less text, and the deleted wording was presented orally by the native navigator. A photograph was added of three Comanche men standing in front of a teepee, which has ceremonial and cultural symbolism to the Comanche people. The Comanche men in the slide live in the community where the workshops will take place, which adds familiarity for participants. Many slides in the module were deleted, so only the major points were conveyed. This helped to maintain the attention of focus group participants. In addition, data regarding cancer among men from the southern plains were discussed, which is the area in which the Comanche people live.

Implications for Nursing

The model of tailoring cancer-related educational modules and goals to the Comanche Nation may be transferable to other NA communities. In particular, that may apply to those who have similar cultures, such as the Shoshone, a tribe from which the Comanche descended.

Oncology nurses who work with NA patients need to be aware of cultural practices of the tribal members they serve to build reciprocal respect and trust. Nurses should accommodate NA patients who want to consult with a traditional healer or participate in healing ceremonies, in addition to encouraging Western medicine.

When explaining cancer screening procedures to patients, nurses should choose terms that are understandable and respond to questions and concerns so the patients feel empowered by having their voices heard. When receiving health histories, nurses should share information about personal habits or family history that may put them at risk for cancer and acknowledge health habits that serve as protective factors against cancer to reinforce healthy behaviors. Oncology nurses can foster healthy behaviors by encouraging traditional cultural practices (e.g., dancing at powwows, hunting activities) that serve as healthy exercise. Nurses can assess which behaviors the patient wants to focus on to create individual, realistic, and achievable goals.

When providing bedside, clinic, or community teaching to NA patients, creation of cancer-related educational materials needs to incorporate interactivity to facilitate engagement. Content needs to be modified so the tribal people maintain interest, which includes choosing relevant topics and discussing them in a culturally respectful manner.

Conclusion

The current study has been successful in large part because it employed a CBPR approach. The PI had to suspend judgments regarding what constituted robust cancer-related educational sessions and the qualifications required for facilitating a focus group. At every step in the project, the PI needed to stop and ask for input and permission from Comanche staff and community members and was always willing to extend a welcoming hand to Comanche people to join in and participate, even if extra education and effort was required.

Although the PI also calls the Comanche community home, the perspectives of those who have grown up in the community are different. Community members may be of varying ages, different ethnicities, and diverse educational backgrounds, which can add depth and richness to an educational program.

Comanche people have not been included in educational strategies to decrease cancer incidence and mortality in previous studies. This article described the process of tailoring cancer-related educational modules to the Comanche Nation and creating goals to facilitate cancer-related behavioral change.

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Implications for Practice

- ▶ When working with Native American (NA) patients, be aware of cultural practices of the tribes they serve to build respect and trust.
- ▶ Choose terms that are understandable when explaining cancer screening procedures, and respond to questions and concerns so patients feel empowered by having their voices heard.
- ▶ Incorporate cultural and interactive aspects in cancer-related educational materials to facilitate engagement when providing bedside, clinic, or community teaching to NA patients.

- What do you think about this slide presentation?
- Is there any information or photographs/graphics that you think should be deleted?
- Is there any information or photographs/graphics that you think should be added?
- Please provide any advice that you think would be helpful to make the slide presentation culturally appropriate and appealing to members of the Comanche Nation.
- What do you think about the interactive activity in this presentation?
- What do you think about the goals at the end of this presentation?

FIGURE 1.
Interview Guide

FIGURE 2.

Model of Developing Cancer-Related Educational Content and Goals Tailored to the Comanche Nation

TABLE 1

Sample Characteristics (N = 23)

Characteristic	n
Race or Ethnicity	
Native American	22
Caucasian	1
Gender	
Female	16
Male	7
Age (years)	
18–20	1
21–30	1
31–40	7
41–49	4
50–64	7
65–80	3
Education	
Some high school	1
High school diploma or GED	9
Some college	5
Associate's degree	3
Bachelor's degree	4
Master's degree	1